

CenterLines

Center for Disabilities and Development *Useful News for Families*

Leaving Nothing to Chance

Sydney Von Lehmden's teachers knew a lot about her before she set foot in her new school. It was 2011, when the fifth grader was getting ready to make the transition from grade school to middle school.

At best, the transition for a child with special needs is challenging. But Sydney's mother, Kelly, was determined to make it as pain free as possible. So she wrote a short book directed to Sydney's Individualized Education Program (IEP) team.

The book contained photos of Sydney and her family. And more important, it contained information that would help the team get to know the girl inside and out, long before the first bell rang.

"When you have a plan ahead of time, you reduce the stress for everyone," Kelly said. "If I'm not worried, it will help Sydney. Particularly when it's a big transi-



tion year, I like to give information about Sydney and her family, what she likes to do, what Sydney may be nervous about."

Two years later, Sydney, now an eighth-grader at Oak Ridge Middle School in Marion, is comfortable with her surroundings and eager to start class again. But that doesn't mean that Kelly, a former chairwoman of the Special Education Advisory panel, sits back.

"For the parent, we are always nervous about the school year," she said. "We worry about her schedule – do the classes make

sense? And how do we make sure she has quality peer interaction? We also want to make sure lunch is not stressful, and that she has friends to sit with. We want to give her as much independence as possible."

Sydney's teacher, Annette Saxion, is every bit as proactive as Kelly. "Before school starts, I email parents or call them and invite them to come in." Annette even takes the initiative with the students. "If the student is capable, I like to start an email conversation before school starts," she said. I put them at ease and I learn something about them."

"It's my job to make them feel comfortable. When they are nervous, it's impossible for them to perform in their studies very well."

Ongoing teacher-parent communication needs to be agreed upon at the beginning of the school year. "We need to establish with the teacher how we're going to communicate, whether a daily note, email, phone call," Kelly said.

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University of Iowa Health Care



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And of course, the student's IEP needs to be examined – by all who work with students with special needs. "I feel good when the IEP is looked at by everyone, not just the special education teacher," said Kelly.

And what happens in a year when Sydney becomes a freshman at Linn-Mar High School? "I will have another book ready to go," Kelly said. "You can count on that."

Write your own book

Write what you know about your child – no more than four pages. This will help school employees – from special education teachers to their peers in general education – successfully guide your child's school experience.



Here are some good topics:

- History (family)
- Health history
- Therapy
- Personality (describe the child you know)
- Strengths
- Areas that need shoring up (such as "social skills")
- Child's specific needs (academic, peer/adult support)
- Parents' concerns and fears (such as low expectations among staff, child eating lunch alone or riding bus)
- Parents' expectations (such as grade-level performance)

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Liquid Ritalin

You can now get Methylphenidate in a liquid form. (Methylphenidate is the generic name. Ritalin, Concerta, Daytrana, Methylin and Metadate are all kinds of Methylphenidate.) It will have the same possible side effects that other kinds of Ritalin can have. That includes problems with not wanting to eat, tics, headaches, tummy aches, and irritability.

One liquid form is called Quillivant XR. You need to shake it very well before using it. It only needs to be given once a day. Another liquid form is Methylin solution. It is short acting. You would need to give it 2-3 times a day. There is a chewable tablet of Methylin that is also short acting.

Medicaid does not cover any of these unless you can prove that you have tried both short and long acting kinds of their preferred meds. Other insurance companies may not want to pay for them either. Some kinds of Methylphenidate can be opened and sprinkled on a spoonful of food like applesauce. Focalin and Ritalin LA can be opened and sprinkled. Concerta, Ritalin SR and Metadate CD must be swallowed whole. Some of the other stimulant medicines, like Adderall and Vyvanse can also be opened and sprinkled if your child has a hard time swallowing pills.

The chewable tablet and liquids are meant to taste good. Be sure you keep them where your child cannot get to them and take too much.

ICATER ToolKit app

The Iowa Center for Assistive Technology Education and Research (ICATER) developed a free application for Apple products called the ICATER ToolKit. This gives you access to two of their projects, the Weekly AT App Reviews and the AT Tips



of the Day. In the Reviews, users will be able to view short, simple webinars of different apps that can be used to help students who have disabilities. The AT Tip of the Day will let users see short nuggets of information on assistive technology that can be used in education. You will also get a link to the ICATER website and a Twitter feed. You can use this to request an app be reviewed. For more information go to <https://itunes.apple.com/us/app/icater-toolkit/id686511315>.

New CDD Outreach Clinic

CDD recently initiated a new Outreach clinic in the Quad Cities (Bettendorf). Drs. Royann Mraz, Deb Lin-Dyken, Dianne McBrien, and Andrea Reasoner evaluate and follow children with ADHD, autism spectrum disorders, developmental delays, speech delays, learning problems, and genetic syndromes. We do an initial evaluation and make recommendations for treatment and/or further evaluation. We also follow patients for medication management.

To make a referral or get more information you can call our Scheduling Center at 877-686-0031.

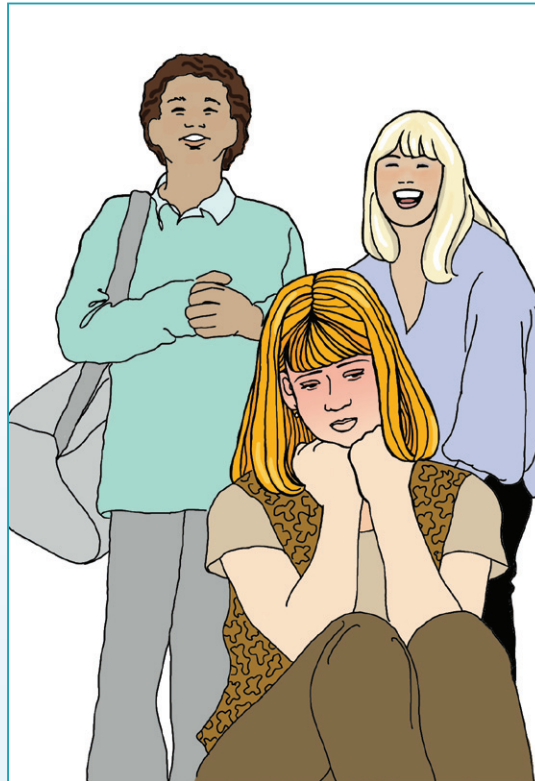


Stop the Bullying

Everyone has probably been bullied at some point in their life. We hear about kids being bullied, but adults can be bullied too. Unfortunately, kids have a harder time rising above it and being strong. Bullies are aggressive. They make threats, spread rumors, hit, or call names. If a child is being excluded from a group on purpose, that is also bullying. It can happen in person, on the phone, and on the computer, and it goes on for a long time. It happens to kids who are different from others, those who don't fit in – including children with disabilities.

Kids who are bullied can suffer from mental health problems, such as low self-esteem, stress, depression, or anxiety. They may think about suicide. They stop doing well in school and are scared to even go. Children who are bullied can grow up with long-term health problems.

Who is the bully? Many bullies like to control others and only care about themselves. They often have poor social skills and don't know how to play or work with other children. Sometimes they've been bullied too. They bully others to fit in. Or, they may be getting bullied at home by their parents or siblings. So, they lash out at others to feel better and to feel power.



What can you do if you're being bullied? First, walk away. Don't get upset or angry. That is what they want. The bully wants to

see that they got to you. Don't get physical. It isn't a good idea to fight. You never know what they will do next. Always tell an adult. They may not see the bullying or know it's going on. Talk about it with your friends, family, and maybe a school counselor. Talking will help you work on the problem and will make you feel better. You are not alone.

We all need to work together to stop bullying. If we bring it into the open we can work on it and hopefully see it end. To learn more go to these online resources:

www.stopbullying.gov,

www.PBSkids.org/itsmylife/friends/bullies/, and

www.kidshealth.org.

Do you have health insurance?

The Affordable Care Act (ACA) begins on January 1, 2014. The Healthcare Marketplace began open enrollment on October 1 and will end March 31st. To find out whether or not you will have to pay for insurance or you might be exempt go to www.healthcare.gov and read about this program. Know the law and what you need to do. Make sure you are covered. You can also find out if you might be qualified for Medicaid or the Children's Health Insurance Program (CHIP). Healthcare.gov takes you through the steps and explains all the rules. You can also "chat" with someone live on the site if you cannot find the answers you need.



New Programs at CDD

We are pleased to announce two new programs at the Center for Disabilities and Development.

Transitioning youth with special health care needs from pediatric orientated health care to the adult service system

We recognize there is a lot of work preparing a child to move into the adult world. This clinic works with families providing the tools and resources so their child becomes a healthy adult. We work with them over time and monitor their progress and skill development. Our pediatricians are here to assure a safe and seamless transfer of medical care to their adult physician when appropriate.

- We start early with 12 year-olds to assure adequate time to learn and practice skills
- Our transition services are family centered, we work with the family to write an action plan
- We provide resources, tools, and education, and regularly monitor a youth's progress with skill development and readiness to accept adult roles and responsibilities
- We help identify and work with adult care providers for a smooth transfer of care
- We also work on guardianship and living arrangements; health insurance coverage; mental health; relationships and sexuality; nutrition; activities of daily living and physical activity

Social Skills Groups

These groups will help teach children how to talk, play, and work with others. It is important for children to learn how to be social, but they can't do that alone. The group gives them the chance to work with other children and practice. During the first 8-week session, the focus will be on how to be part of a group. That includes how to:

- Learn the right behavior
- Listen with your whole body
- Look for cues (facial expressions, body language)
- Learn to play with other kids

The social skills group is for school-aged students, 7-12 years, who have problems with their social skills and who have near-normal to above average intelligence. These children could have high-functioning autism, PDD, Asperger's, and non-verbal learning disorders. The social skills group will meet once a week for 8 weeks. Each meeting will be from 4-5 pm on Thursday afternoons. We will meet at CDD.

Session 1: October 24 – December 19 (*no session the week of Thanksgiving*)

Session 2: January 16 – March 13 (*no session February 27*)

Session 3: March 27 – May 15

For more information about Social Skills Groups, please contact Jennifer Fitzpatrick at 319-467-6013 with any questions or for a packet with everything you'll need to sign up. You can also email her at jennifer-fitzpatrick@uiowa.edu.

For more information or to make an appointment, contact:

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877-686-0031 (toll-free) • 319-353-6900 (local)
cddscheduling@uiowa.edu • www.uichildrens.org/cdd

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CenterLines for Families, the newsletter of the Center for Disabilities and Development at the University of Iowa Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting people with disabilities, and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uichildrens.org/cdd. Click on Centerlines for Families.

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The role of the information in this newsletter is not to provide diagnosis or treatment of any illness or condition. We strongly encourage you to discuss the information you find here with your health care and other service providers.